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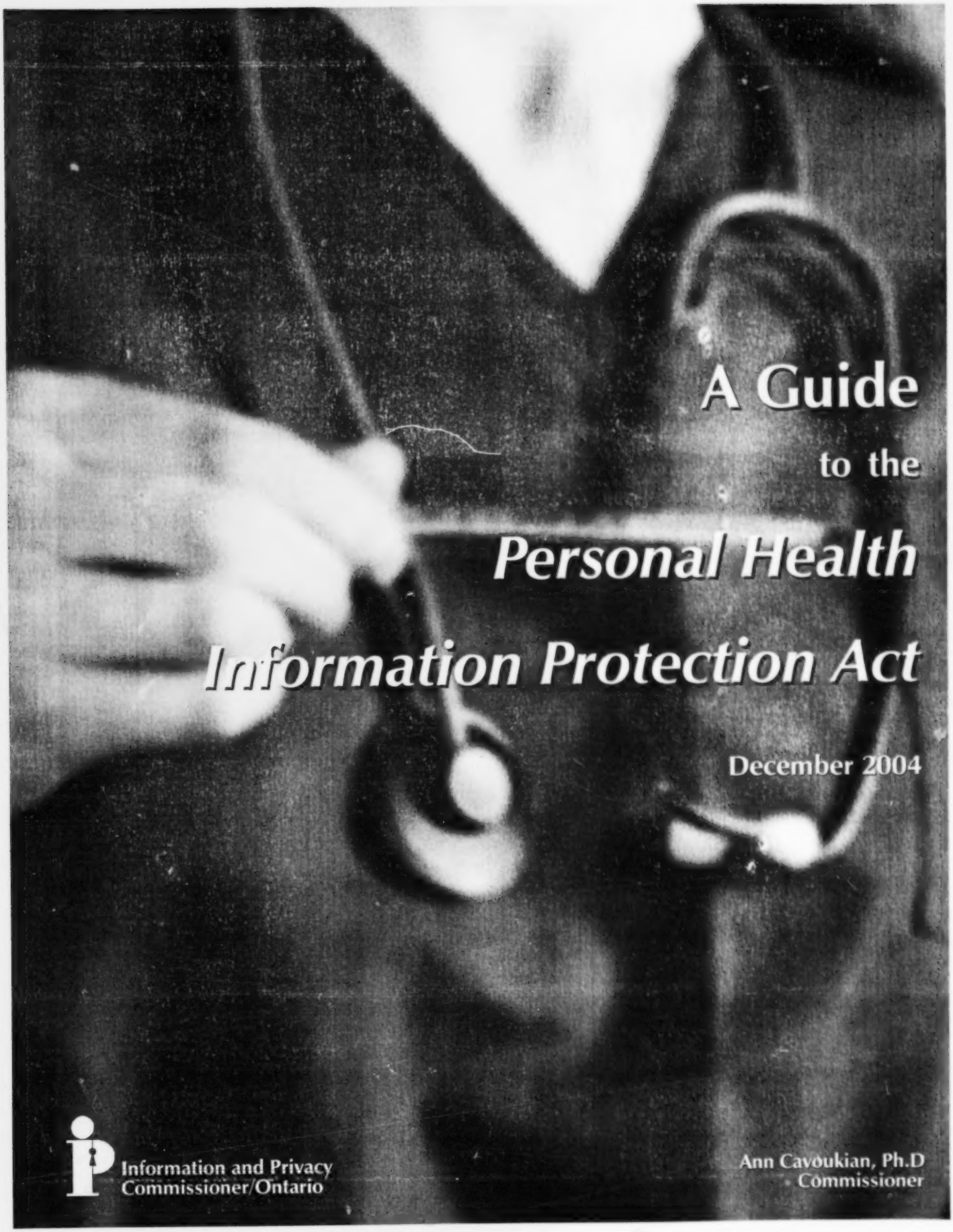

A Guide to the *Personal Health Information Protection Act*

December 2004

Information and Privacy Commissioner/Ontario

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Commissioner

Dr. Ann Cavoukian, the Information and Privacy Commissioner of Ontario, gratefully acknowledges the work of Debra Grant in preparing this guide.

This publication is also available on the IPC website.

Cette publication est également disponible en français.

Disclaimer

This practical guide is based on the *Personal Health Information Protection Act* and its regulations. The interpretation of this legislation in this guide should not be relied upon as a substitute for the legislation or legal advice. This guide should be used in conjunction with the *Personal Health Information Protection Act*. This guide is not an official legal interpretation of the legislation and is not binding on the Office of the Information and Privacy Commissioner of Ontario.

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Introduction

The *Personal Health Information Protection Act* sets out rules for the collection, use and disclosure of personal health information. These rules will apply to all health information custodians operating within the province of Ontario and to individuals and organizations that receive personal health information from health information custodians. The rules recognize the unique character of personal health information – as one of the most sensitive types of personal information that is frequently shared for a variety of purposes, including care and treatment, health research, and managing our publicly funded health care system.

The legislation balances individuals' right to privacy with respect to their own personal health information with the legitimate needs of persons and organizations providing health care services to access and share this information. With limited exceptions, the legislation requires health information custodians to obtain consent before they collect, use or disclose personal health information. In addition, individuals have the right to access and request correction of their own personal health information.

The purpose of this guide

This guide was created to give health information custodians a basic understanding of how the *Personal Health Information Protection Act* (the *Act*) applies in the course of day-to-day activities.

This guide has been designed to help health information custodians understand their rights and obligations under the legislation. The guide provides information about how the legislation will apply in some common scenarios and provides answers to the most frequently asked questions of health information custodians. The guide will not answer every potential question that a health information custodian may have about the application of the *Act*. The user can refer to the comprehensive Table of Contents or the Quick Reference Guide for answers to common questions.

The guide is not intended to provide a comprehensive explanation of the *Act*. The guide describes the major rights and duties established by the *Act* and the general rules for a health information custodian to follow in exercising those rights and fulfilling those duties.

Suggestions are made about how to apply the *Act* in different situations that may arise in practice. The guide is not a substitute for legal advice. If you are not sure how the *Act* should be applied in a given situation, you should contact the person in your organization who is responsible for facilitating compliance with the *Act*, a lawyer, the Ministry of Health and Long-Term Care, or the Office of the Information and Privacy Commissioner of Ontario.

Important points made in this guide are emphasized with **boldface** type. Words or phrases with a specific meaning under the *Act* are printed in *italics*. These words are defined in the glossary at the end of the guide. **Please pay particular attention to the definitions in the *Act*,** as they are extremely important for determining basic issues such as what information is subject to the *Act* and who is subject to the *Act*.

An overview

The *Personal Health Information Protection Act* is an in-depth piece of legislation designed to address very complex issues concerning the *collection*, *use* and *disclosure* of *personal health information* by *health information custodians*.

Individuals are very concerned about how their *personal health information* is *collected*, *used* and *disclosed*. They expect their *health care* providers to protect this information and not to *use* or *disclose* it, intentionally or inadvertently, for purposes not related to their care and treatment. But, at the same time, it is generally understood that some information is needed to manage our publicly funded *health care* system, for health *research* and other purposes that have social value. Family members, the law enforcement community, medical officers of health, and others may also have a legitimate need to access *personal health information*, under limited and specific circumstances. The *Act* sets out rules to balance different interests in circumstances where the needs of other parties may affect or conflict with the *individual*'s right to privacy. The object of the rules is to maximize both the benefits of respecting privacy and the benefits of *collecting*, *using* and *disclosing personal health information* for purposes that go beyond the care and treatment of the individual, but are socially beneficial.

The *Act* is divided into nine parts, each dealing with a different topic. These topics include:

- Interpretation and application;
- Practices to protect *personal health information*;
- Consent concerning *personal health information*;
- *Collection*, *use* and *disclosure* of *personal health information*;
- Access to records of *personal health information* and correction;
- Administration and enforcement;
- General;
- Complementary amendments;
- Commencement and short title.

The *Act* does not require *health information custodians* to completely set aside their existing *information practices*. *Health care* providers are bound by professional codes of practice that protect privacy. In many respects, the *Act* will not conflict with the pre-existing codes of practice and *health care* professionals should continue to follow these codes. However, where there is a conflict and the *Act* prohibits a practice that a professional code would allow, *health care* professionals are legally bound to comply with the *Act*.

In most cases, the *Act* will require changes to the existing *information practices* of *health information custodians*. However, **it is important to note that the *Act* has been designed to enhance privacy while minimizing the impact on the patient-provider relationship.**

Does the *Act* apply to you?

General

The *Act* will have an impact on every *individual* residing in the province of Ontario. In general, the *Act* will provide *individuals* with more control over how their *personal health information* is *collected*, *used* and *disclosed* by *health information custodians*. With some exceptions, *individuals* will be able to access and request correction of their own *personal health information*.

The *Act* does not apply to all *personal health information*, but only that which is *collected*, *used* and *disclosed* by *health information custodians*. The *Act* also applies to the *use* and *disclosure* of *personal health information* by those *persons* who receive *personal health information* from *health information custodians*. For example, recipients may include insurance companies, employers, researchers, and others. Those who perform services on behalf of a *health information custodian* are defined as *agents*. *Agents* of *health information custodians* are also required to follow the rules set out in the *Act*.

Are you a custodian?

The *Act* defines a *health information custodian*. Seven broad categories of *health information custodians* are included in the definition. In general, *persons* involved in delivering health care services are included. For example, *health care practitioners*, long-term-care service providers, community care access corporations, hospitals and other facilities, pharmacies, laboratories, a medical officer of health or a board of health, the Ministry of Health and Long-Term Care, and others are specifically included in the definition. It is important to note that ***health care practitioners* include anyone who provides *health care* for payment, whether or not the services are publicly funded.** The Canadian Blood Services has been designated as a *health information custodian* by regulation. Others can be added to this list as necessary. *Health information custodians* will be referred to as custodians throughout the balance of this guide.

Are you an *agent* of a custodian?

Under the *Act*, you are considered to be an *agent* if, with respect to *personal health information*:

- you are authorized to act on behalf of a custodian; and
- you perform activities for the purposes of a custodian rather than your own purposes;
- whether or not you have the authority to bind the custodian;
- whether or not you are employed by the custodian; and
- whether or not you are receiving remuneration.

For example, *agents* may include employees, volunteers, information processors, and information managers. It is important for *persons* to determine if they are *agents* so that they will know if they are bound by the *Act*. **It is also important for custodians to identify their *agents* and appropriately inform them of their duties under the *Act*.**

Do you provide information technology services to a custodian?

The *Act* also includes a number of requirements for service providers, some of whom may not be considered to be *agents* of the custodian. If you are not an *agent* of the custodian, but provide goods or services that enable the custodian to use electronic means to *collect*, *use*, modify, *disclose*, retain or dispose of *personal health information*, you must comply with certain restrictions on the *use* and *disclosure* of that information that are set out in the regulations that accompany the *Act*. In addition, whether or not you are an *agent* of the custodian, if you are a health information network provider that enables custodians to share *personal health information* by electronic means, you must fulfil a number of duties that are set out in the regulations. These requirements are discussed in more detail later in this guide.

Are you a recipient?

The *Act* applies to the *use* and *disclosure* of *personal health information* by *persons* who receive the information from a custodian, regardless of when the information was received. **It is important to know if you have received *personal health information* from a custodian since the *Act* places restrictions on what recipients may do with that information.** Provincial and municipal government organizations that are not custodians are not bound by the restrictions the *Act* places on other recipients of *personal health information*.

Example 1: Does the *Act* apply to you?

A registered nurse works for a private company involved in the manufacture of goods using chemicals that can be toxic to *individuals* after prolonged exposure. The nurse has been hired to regularly test employees of the company for levels of various toxins to determine whether it is safe for the employees to continue working under conditions where they are exposed to these chemicals. Once certain levels of toxins are detected in their blood, employees are transferred to other divisions of the company where there is no exposure to these chemicals. On a monthly basis, the nurse provides a report to the management of the company specifying whether it is safe for each employee to continue working under conditions of exposure. The information obtained by the nurse from testing of the employees is used for no other purpose. Is the nurse subject to the *Act*?

Is the manufacturing company a *health information custodian*?

The manufacturing company is not a custodian since such companies are not included in the list of *persons* and organizations set out under the definition of a *health information custodian* contained in the *Act*.

Is the nurse a *custodian*?

A registered nurse is a *health care practitioner*, which is included in the list of persons and organizations set out under the definition of a custodian in the *Act*, so the nurse in this scenario **could** be a custodian. Whether the nurse is a custodian would be determined by whether the information that is collected, used or disclosed by the nurse is *personal health information* as defined in the *Act* and whether the scope of the nurse's duties includes the provision of *health care*.

Is the information *personal health information*?

The definition of *personal health information* includes information that relates to the provision of *health care* to individuals. *Health care* is broadly defined to include an assessment that is done for a health-related purpose and that is carried out to maintain an *individual*'s physical condition. Accordingly, this information would be included, unless it is subject to an exception.

Is the information subject to an exception to the definition of *personal health information*?

Information contained in a record that relates to an employee of a custodian that is maintained for a purpose other than the provision of *health care* is excluded from the definition of *personal health information*. Since, in this scenario, the employees of the manufacturing company are not employees of the custodian (i.e., the nurse) and the information is used primarily for the purpose of providing *health care* to the *individuals*, the information is not subject to the exception. The nurse, and the *personal health information* that she *collects*, *uses* and *discloses*, **are** subject to the *Act*.

What information does the *Act* protect?

The *Act* applies to *personal health information* that is *collected*, *used* or *disclosed* by custodians. *Personal health information* includes **oral or written information** about the individual, if the information:

- relates to the *individual's* physical or mental health, including family health history;
- relates to the provision of health care, including the identification of *persons* providing care;
- is a plan of service for *individuals* requiring long-term care;
- relates to payment or eligibility for health care;
- relates to the donation of body parts or bodily substances or is derived from the testing or examination of such parts or substances;
- is the *individual's health number*; or
- identifies an individual's *substitute decision-maker*.

Any other information about an *individual* that is included in a *record* containing *personal health information* is also included in the definition. Employee *records* of a custodian are excluded from the definition provided that the *records* are used primarily for purposes other than providing *health care*. Also, the *Act* does not apply to information about an *individual*, if the information could not reasonably be used to identify the *individual*.

Example 2: What information does the *Act* protect?

An insurance company maintains records of prescription drug claims for *individuals* enrolled in group health insurance plans. *Individuals* submit their claims for prescription drugs directly to the insurance company. Is this information subject to the *Act*?

Is the information *personal health information*?

The information in question is identifying information that relates to the provision of *health care* to the *individual*. As such, it would fall within the types of information included in the definition of *personal health information*. However, the *Act* only applies to *personal health information* if it is in the custody or control of a custodian, or in the custody or control of an *individual* or organization who received it from a custodian.

Is the insurance company a *health information custodian*?

Insurance companies are not included in the definition of a custodian. Since the information is not in the custody or control of a custodian, it would not be subject to the *Act* **unless** the insurance company received the information from a custodian.

Is the insurance company a recipient of personal health information from a custodian?

Since the insurance company obtains the information directly from the individual, the insurance company is not subject to the rules that would apply to *persons* and organizations that receive information from a custodian.

Practices to protect personal health information

General

Custodians must implement and follow *information practices* that comply with the *Act* and its regulations. *Information practices* mean the policy about when, how and the purposes for which the custodian routinely *collects*, *uses*, modifies, *discloses*, retains or disposes of *personal health information* and the administrative, technical and physical safeguards and practices that the custodian has in place.

Custodians must take **reasonable** steps to ensure that *personal health information* is as accurate, complete and up-to-date as necessary for the purposes for which it is used and disclosed. Custodians must exercise their judgment in deciding how accurate the information should be. For example, *personal health information* that is *used* for treatment purposes may require a higher degree of accuracy than information that is *used* for administrative purposes only. Custodians must also inform recipients of *personal health information* about any limitations on the accuracy of the information.

Custodians must take steps that are **reasonable in the circumstances** to ensure that *personal health information* in their custody or control is protected from theft, loss and unauthorized *use* or *disclosure*. *Records* of *personal health information* must also be protected against unauthorized copying, modification or disposal. The custodian must notify *individuals* if *personal health information* is stolen, lost or accessed by an unauthorized *person*. However, custodians who are *researchers* and received *personal health information* from another custodian should not notify *individuals*, unless the other custodian informs the *researcher* that the *individual* has consented to being contacted by the *researcher*.

Information Technology Service Providers

Persons who provide services to enable a custodian to use electronic means to *collect*, *use*, modify, *disclose*, retain or dispose of *personal health information*, but are not *agents* of the custodian, must comply with restrictions on the *use* and *disclosure* of that information. Specifically, the information cannot be *used*, except as necessary in the course of providing the service, or *disclosed* under any circumstances. Service providers must ensure that their employees or any other person acting on their behalf comply with the restrictions that apply to service providers.

In addition, whether or not you are an *agent* of the custodian, a health information network provider who provides information technology that allows two or more custodians to share personal health information electronically must:

- Notify the custodian of any breach of the restrictions on its *use* and *disclosure* of *personal health information* or unauthorized access;
- Make available to the public, information about the services provided to the custodian; any directives, guidelines and policies of the provider that apply to the services provided; and a general description of the safeguards that have been implemented;
- Provide to the custodian, upon request, an electronic record of all accesses and transfers of *personal health information* associated with the custodian;
- Perform and provide to the custodian a threat risk assessment and privacy impact assessment of the services provided;
- Ensure that any third parties that you retain comply with the restrictions and conditions necessary for the provider to comply with its requirements; and
- Enter into an agreement with the custodian that describes the services provided; describes the administrative, technical and physical safeguards; and requires the provider to comply with the *Act* and its regulations.

It is important to note that the provision of *personal health information* by a custodian to a service provider, that is not an *agent* of the custodian, is not considered to be a *disclosure* as long as the restrictions and conditions set out in the regulations are complied with.

Records

Custodians must ensure that *records* are retained, transferred and disposed of in a secure manner. *Records* to which an *individual* has requested access must be retained until all procedural matters relating to that request are completed. This could include a potential complaint to the *Commissioner*. *Records* may be kept in an *individual's* home or in another place, provided the *record* is kept in a **reasonable** manner and the *individual* consents. *Health care practitioners* should refer to the legislation and regulations governing members of their profession for additional information on record keeping.

Accountability and Openness

To enhance accountability, custodians must designate a **contact person** who is authorized to:

- help the custodian to comply with the *Act*;
- ensure that all *agents* are informed of their duties under the *Act*;
- respond to inquiries about the custodian's *information practices*;
- respond to requests for access or correction of *records*; and
- receive complaints about contraventions of the *Act*.

Where the custodian is an individual (a natural person, not a company or an institution), the custodian may perform the functions of the contact person.

To enhance transparency, the custodian must make available to the public a **written statement** that describes:

- the custodian's *information practices*;
- how to reach the contact person or the custodian, if the custodian does not have a contact person;
- how an *individual* may obtain access to or request correction of a *record*; and
- how to make a complaint to the custodian and the *Commissioner*.

With some exceptions, whenever *personal health information* is *used* or *disclosed* in a manner that is not described in the custodian's *information practices*, the custodian must: inform the *individual* of the *use* or *disclosure*; make a note of the *use* or *disclosure* in the *records* of *personal health information*; and keep the note as part of the *records* or in a form that is linked to the *records*.

The custodian may permit an *agent* to carry out certain activities in relation to *personal health information* on behalf of the custodian. Except as permitted or required by law, an *agent* may only perform functions that the custodian is permitted or required to carry out. An *agent* must notify the custodian if *personal health information* that is being handled by the *agent* is stolen, lost or accessed by unauthorized *persons*.

Consent concerning personal health information

Under the legislation, **consent may be express or implied**. When a custodian *discloses personal health information* to another custodian for the purpose of providing *health care*, the consent of the individual may be implied, unless the individual has specifically withheld or withdrawn the consent. If the purpose of the *disclosure* is not to provide *health care*, consent must be express. Also, consent for *disclosures* to third parties that are not custodians must be express.

One exception to the express consent requirement is where a health care facility is *disclosing personal health information* about a patient or resident to a representative of a religious or other organization. If the *individual* has provided information about his or her religious or other organizational affiliation, consent may be implied for disclosing the *individual's* name and location in the facility to the representative. Before making this *disclosure*, the facility must provide the *individual* with an opportunity to withhold or withdraw the consent.

Another exception to the express consent requirement is where a pharmacist is disclosing *personal health information* to a third party who is being asked to provide payment for medication or related goods or services.

Safeguards have been built into the legislation to help minimize any potential adverse effects when the individual withdraws consent. Specifically, where a custodian *discloses personal health information* to another custodian for the purpose of providing *health care* to the *individual* and the custodian does not have consent to *disclose* all of the information that the custodian believes is necessary for that purpose, the custodian must notify the recipient of this. Also, a custodian may *disclose personal health information* without consent where the custodian believes on **reasonable grounds** that that the *disclosure* is necessary to eliminate or reduce a significant risk of bodily harm to one or more *persons*.

Whether it is express or implied, consent must be **knowledgeable**. This means that the *individual* must know the purpose of the *collection*, *use* or *disclosure* and that consent may be provided or withheld. A custodian may assume that the *individual* is knowledgeable if the custodian posts or makes readily available a notice describing the purposes, where it is likely to come to the *individual's* attention. A custodian may assume that a consent fulfills the requirements of the *Act*, unless it is **not reasonable** to make this assumption.

Example 3: When can you rely on implied consent?

A general practitioner has received abnormal test results for a patient and would like to refer the patient to a specialist. Does the general practitioner need the patient's express consent or can he rely on implied consent to schedule the appointment and forward the test results to the specialist?

Can the general practitioner rely on implied consent in this case?

Since the disclosure of *personal health information* is to another custodian or its *agent* for the purpose of providing *health care* or assisting in providing *health care* to the *individual*, the general practitioner may rely on implied consent, **unless** the custodian is aware that the *individual* has expressly withheld or withdrawn the consent.

Capacity and substitute decision-making

An *individual* is *capable* of consenting to the *collection*, *use* or *disclosure* of *personal health information* if the *individual* is able to understand the relevant information and the consequences of giving or withholding consent. A custodian may presume the *individual* is *capable*, unless there are **reasonable grounds** to believe that the *individual* is *incapable* of consenting. If a custodian determines that an individual is *incapable* of consenting, the custodian must provide to the individual information about the consequences of this determination. The individual may apply to the Consent and Capacity Board for a review of the determination of *incapacity*.

The *Act* authorizes other people to act on behalf of the *individual* under specific circumstances. An *individual* who is *capable* may authorize another *person* to act on his or her behalf. With some exceptions, a *parent* may consent on behalf of a child who is less than 16 years of age. If the *individual* is *incapable*, an authorized *substitute decision-maker* may consent on his or her behalf. If the *individual* is deceased, the estate trustee or *person* who is responsible for administration of the deceased's estate may provide consent. A *person* who is authorized or required by law to act on behalf of the *individual*, may provide consent.

If the *individual* is determined to be *incapable* of consenting to the *collection*, *use* or *disclosure* of *personal health information*, the following *persons* may act on his or her behalf:

- the *individual's guardian of the person* or *guardian of property*;
- the *individual's attorney for personal care* or *attorney for property*;
- the *individual's* representative appointed by the Consent and Capacity Board;
- the *individual's spouse* or *partner*;
- a child or parent of the *individual*;
- a parent of the *individual* with only a right of access;
- a brother or sister; or
- any other *relative*.

A *person* may consent on behalf of an *individual* only if no other *person* higher on the above list meets the criteria for consenting on behalf of the *individual*. For example, one of the criteria is that the *person* must be available. The Public Guardian and Trustee may make the decision to consent, if no other *person* meets the requirements.

An *individual* who is 16 years old or older and determined to be *incapable* may apply to the Consent and Capacity Board for appointment of a representative to consent on the *individual's* behalf.

Example 4: Who can act as a *substitute decision-maker*?

A 14-year-old girl has been admitted to a hospital. She was accompanied by her father who does not have custody of his daughter, but has a right of access. The child appears to be suffering from a drug overdose and the father has confirmed that his daughter has a history of drug abuse. The father has demanded that the hospital contact a social worker who has been involved with the child and her family for several years. The child has objected to any *disclosure* of *personal health information* to the social worker. Can her father act as the *substitute decision-maker* for the child?

Can a father with only a right of access act as a *substitute decision-maker*?

In general, a parent with only a right of access cannot consent to the *collection*, *use* or *disclosure* of *personal health information* on behalf of a child who is less than 16 years of age. However, a parent with custody of the child may consent, unless the information relates to treatment about which the child has made a decision on her own or counselling in which the child has participated on her own. One exception to these rules may be where the child was deemed to be *incapable*.

Can a father with only a right of access act as a *substitute decision-maker* if the child was deemed to be *incapable*?

If the child is deemed to be incapable of consenting to the *collection*, *use* and *disclosure* of *personal health information*, a parent of the child with only a right of access to the child may consent only if no other *person* ranked higher on the list of *substitute decision-makers* contained in the *Act* meets the criteria for consenting (e.g., is available and willing to assume responsibility). Other *persons* ranked higher on the list include a parent with custody or the *individual*'s guardian. In this scenario, the father would be able to act as the *substitute decision-maker* only if the child is deemed to be *incapable* of consenting and the father is the *person* highest on the list of *substitute decision-makers* that meets the criteria for consenting on the child's behalf.

Would a parent's wishes override the child's wishes regarding the *disclosure* of *personal health information* to the social worker?

Where there is a conflict between the wishes of a parent who is entitled to act as a *substitute decision-maker* and a child who is deemed to be capable, the child's decision to give, withhold or withdraw consent for a *collection*, *use* or *disclosure* of *personal health information* prevails over that of the parent. The father's wishes regarding the *disclosure* of *personal health information* to the social worker would only prevail if the child is deemed to be *incapable* and the father is the person who is entitled to act as the *substitute decision-maker*.

Collection, use and disclosure of personal health information

General limitations and requirements

The *Act* sets out some general principles that apply to the *collection*, *use* and *disclosure* of *personal health information*. **These principles are important as they apply to most *collections*, *uses* or *disclosures* of *personal health information*, even those that the *Act* permits without consent.** The *Act* must be read with these principles in mind:

- a custodian may only *collect*, *use* or *disclose personal health information* if the *individual* consents or the *collection*, *use* or *disclosure* is permitted or required by the *Act*;
- a custodian must not *collect*, *use* or *disclose personal health information* if other information will serve the purpose;
- a custodian must not *collect*, *use* or *disclose* more *personal health information* than is necessary to meet the purpose;
- express consent is required to *collect*, *use* or *disclose personal health information* for marketing purposes;

Fundraising

- a custodian may *collect*, *use* or *disclose personal health information* for fundraising if the *individual* expressly consents. If the information consists only of the *individual's* name and mailing address (or those of the individual's substitute decision-maker), consent may be implied for fundraising purposes;
- The following requirements and restrictions apply to fundraising:
    - *Personal health information* may only be *collected*, *used* or *disclosed* for activities undertaken for a charitable or philanthropic purpose related to the custodian's activities;
    - Consent may be inferred where:
        - the custodian has provided a brief statement that the *individual's* name and contact information will be used for fundraising purposes, unless the *individual* requests otherwise, together with information about how to opt-out of future fundraising solicitations, and
        - the individual has not opted out within 60 days of the statement being made available;

- All solicitations must provide an easy way to opt-out; and
- Any communications must not include any information about the *individual's health care* or state of health.

Health cards and health numbers

- *persons* who are not custodians must not *collect* or *use* a *health number*, except:
  - for purposes related to the provision of *provincially funded health resources*;
  - for the purposes for which a custodian has disclosed the number to the person;
  - for purposes related to regulating health professionals; or
  - for purposes relating to health administration, health planning, health research or epidemiological studies (only applies to *persons* prescribed by regulation, such as the Workplace Safety and Insurance Board, Cancer Care Ontario, Canadian Institute of Health Information, and the Institute for Clinical Evaluative Sciences).
- *persons* who are not custodians must not *disclose a health number*, except as required by law.

Persons who are not custodians may *disclose* the *health number* in a limited number of circumstances set out in the regulations, such as for a purpose related to the provision of *provincially funded health resources* and for certain *research* related purposes.

The preceding restrictions do not apply in situations where the *health number* is *collected*, *used* or *disclosed* for the purposes of a proceeding; planning and management of the health system; and health system analysis by a health data institute.

Only *persons* who provide *provincially funded health resources* may require *individuals* to produce their *health cards*.

Example 5: Can *personal health information* be *used* for fundraising activities?

A charitable foundation for a children's hospital has been asked to raise money to support a large *research* project on a specific childhood genetic disorder. To make the campaign for funds as effective as possible, the foundation has decided to solicit funds only from families affected by this particular disorder. The foundation has asked the hospital for the contact information of the parents of children who have been identified as having this genetic disorder. Is the hospital permitted under the *Act* to provide this information to the foundation?

Is the parents' contact information considered to be *personal health information*?

Under the *Act*, *personal health information* includes identifying information about an *individual* if the information relates to the physical or mental health of the *individual*, including information that consists of the health history of the *individual*'s family. Thus, parental contact information combined with information about a child's genetic disorder would be considered to be the *personal health information* of both the child and the parent.

Is the hospital permitted to provide *personal health information* to the foundation for fundraising purposes?

Since the hospital foundation is fundraising on behalf of the hospital, the foundation is considered to be an *agent* of the custodian and the provision of *personal health information* to an *agent* of the custodian is considered to be a *use* by the custodian rather than a *disclosure* to the *agent*. Under the *Act*, custodians may *use personal health information* for the purpose of fundraising activities only where the *individual* expressly consents or the consent of the *individual* can be implied, from the circumstances, and the information consists only of the *individual*'s name and contact information (as specified in the regulations). In this scenario, consent for the use of the information for fundraising may be implied, but only if the information that will be used is limited to *individuals'* contact information.

Is the information that will be used limited to *individuals'* contact information?

Since the fact that one or more of the *individual*'s children has a specific genetic disorder will be used to compile a list for the purpose of targeted fundraising, the information that will be used is not limited to contact information. Accordingly, the conditions for implying consent to use the information for fundraising purposes in this scenario have **not** been met. The custodian would have to seek express consent for this type of targeted fundraising activity.

Collection

As a general rule, custodians should *collect personal health information* directly from *individuals*. The *Act* allows custodians to collect information indirectly, under limited and specific circumstances. A custodian may collect information indirectly if:

- the *individual* consents;
- the information is necessary for the provision of *health care* and direct collection is not **reasonably** possible;
- the custodian is a provincial or municipal government institution and the information is needed for an investigation, *proceeding* or statutory function of the custodian;
- the custodian collects the information from a person who is not a custodian for *research* purposes;
- the custodian collects the information from a *person* who is not a custodian for planning and management of the health system (only applies to custodians prescribed by regulation);
- the *Commissioner* authorizes the indirect *collection*;
- the custodian *collects* the information from a *person* who is permitted or required by law to *disclose* it to the custodian; or
- the custodian is permitted by law to *collect* the information indirectly.

Example 6: What information is a custodian authorized to *collect* from *individuals*?

A man comes into a physician's office seeking treatment for a skin irritation. The attending physician is the principal investigator for a *research* project examining the relationship between certain genetic factors and diabetes. The physician routinely *collects* and analyzes blood samples from all of his patients for the purposes of the *research* project. Is this type of *collection* of personal health information permitted under the *Act*?

What are the rules that a custodian must follow in *collecting personal health information*?

In general, custodians may only *collect personal health information* with the consent of the individual for a lawful purpose or as permitted or required by the *Act*. Since the *Act* does not specifically permit or require the custodian to *collect personal health information* directly from the *individual* for *research* purposes without the *individual*'s consent, the custodian could only *collect* the information with the *individual*'s consent.

Could the physician rely on implied consent for this collection?

Under the *Act*, consent to the *collection*, *use* or *disclosure* of *personal health information* may be either express or implied, but for either type of consent to be valid, all of the requirements for consent have to be met. Specifically, the requirements are that the consent must be: knowledgeable, given by the *individual*, relate to the information and not be obtained through deception or coercion. Accordingly, the physician would be permitted to rely on implied consent to collect the information for *research* purposes provided that all of the requirements for consent have been met. However, before the custodian would be able to ***use*** or ***disclose*** the *personal health information* that was collected for this purpose, additional requirements under the *Act* would have to be met.

Use

As a general rule, custodians should *use personal health information* only with the consent of *individuals*, unless the *Act* allows the *use* without consent. The *Act* allows custodians to *use* information without consent:

- for the purpose for which it was collected or created;
- for a purpose for which a person is permitted or required by law to *disclose* it to the custodian;
- for planning or delivering programs or services that the custodian provides or funds;
- for the purposes of risk management, error management or improving the quality of care;
- for educating *agents* who provide *health care*;
- for the purpose of disposing of the information or modifying the information to conceal the identity of the *individual*;
- for the purpose of seeking the *individual's* consent, as long as the information consists of name and contact information only;
- for the purpose of a *proceeding*;
- for the purpose of obtaining payment for *health care* or related goods and services;
- for the purpose of *research*, subject to certain conditions; or
- if permitted or required by law.

A custodian may provide *personal health information* to an *agent* of the custodian to *use* for any of the above purposes.

Example 7: For what purposes is a custodian permitted to use *personal health information* without the consent of the *individual*?

A psychologist operates a private practice in a small town. A new hospital has opened in the town and the hospital's board of directors is seeking input from the community on the programs and services that should be provided. The town has asked the psychologist to survey her clients to find out what type of psychological services her clients would like the hospital to provide. The psychologist routinely conducts quality improvement surveys of her clients. The hospital has offered to pay for the next survey, if the psychologist is willing to use the survey as an opportunity to obtain the additional information necessary to plan and deliver psychological services at the hospital. The psychologist has been assured that she will not be required to *disclose* any *personal health information*, but the hospital has asked for the feedback of her clients to be aggregated by the type of psychological disorder with which they have been diagnosed. Would the *Act* permit the use of her clients' *personal health information* for this purposes?

Is the information that is being used to conduct the survey *personal health information*?

Since the psychologist would need to use contact information along with psychological diagnoses of her clients, this information would fall under the definition of *personal health information*.

Is this a permitted use of *personal health information*?

Under the *Act*, a custodian is permitted to use *personal health information* for the purpose of activities to improve the quality of care or to improve or maintain the quality of any related programs or services of the custodian. The custodian may also use *personal health information* to plan or deliver programs or services that the custodian provides or funds, in whole or in part. In this scenario, the custodian is using *personal health information* for the purpose of planning and delivering programs and services that are provided by another custodian. The psychologist could not use the *personal health information* for this purpose, unless the *individuals* consent to this use.

Disclosure

As a general rule, custodians should only *disclose personal health information* with the consent of *individuals*. The *Act* provides for disclosure without consent in a number of situations as follows:

- *disclosures* relating to providing *health care*;
- *disclosures* by a facility that provides *health care*;
- *disclosures* relating to a deceased *individual*;
- *disclosures* for health or other programs;
- *disclosures* related to risks;
- *disclosures* related to care and custody;
- *disclosures* for *proceedings*;
- *disclosures* to a successor;
- *disclosures* related to this or other Acts;
- *disclosures* for *research*;
- *disclosures* for planning and management of health system;
- *disclosures* for monitoring of health care payments;
- *disclosures* for analysis of the health system; and
- *disclosures* with the *Commissioner's* approval.

The conditions and limitations on the *disclosure* of *personal health information* in each of the above circumstances vary. These are briefly described below.

It is important to note that although the *Act* permits the custodian to *disclose personal health information* in many situations, *disclosure* is not required, unless this *Act* or another Act specifically requires the *disclosure*. The *Act* does not relieve the custodian from a legal requirement to disclose, nor does it prevent the custodian from obtaining consent, when it is not necessary under the *Act*.

Disclosures relating to providing health care

A custodian may *disclose personal health information* to *health care practitioners*; long-term-care service providers; and *persons* who operate health care facilities, programs and services, if:

- the *disclosure* is **reasonably** necessary for the provision of *health care*;
- it is not **reasonably** possible to obtain consent in a timely way; and
- the *individual* has not instructed the custodian not to make the *disclosure*.

If the *individual* prevents the custodian from *disclosing* all the *personal health information* that the custodian considers **reasonably** necessary for the purpose of providing *health care*, the custodian must inform the recipient of this fact.

Custodians may also *disclose personal health information* in order to receive funding or payment for services or for the purpose of contacting next of kin, if the *individual* is injured, incapacitated or ill, and unable to give consent.

Example 8: Can a custodian override an *individual*'s express instruction not to *disclose personal health information* for the provision of *health care*?

A student has been receiving psychological treatment at the university's counselling centre. The student's counsellor has noted that the student is severely depressed and also suspects a dependency on prescription drugs. The counsellor believes that there is a risk of suicide and would like to involve the student's family physician and immediate family members in the student's therapy. However, the student has specifically instructed the counsellor not to *disclose* any *personal health information* to any third parties. Over a weeklong break in the academic year, the student calls the counsellor from out of town. The student's speech is slurred and he is talking about ending his own life. Would the counsellor be permitted to *disclose* personal health information to third parties that may be able to intervene in the crisis situation?

Can the counsellor *disclose personal health information*, even though the student has expressly instructed the counsellor not to make the *disclosure*?

In general, a custodian is permitted to *disclose personal health information* to another *health care practitioner* if the *disclosure* is reasonably necessary for the provision of *health care* and it is not reasonably possible to obtain consent in a timely way. One exception to this rule is where the individual has expressly instructed the custodian not to make the *disclosure*. Since the student had expressly instructed the counsellor not to make the *disclosure*, the counsellor could not rely on this provision of the *Act* to *disclose* the information to the student's family physician.

The *Act* also permits a custodian to disclose *personal health information* if the custodian believes on reasonable grounds that the *disclosure* is necessary for eliminating or reducing a significant risk of serious bodily harm to a person. There are no restrictions on the types of persons to whom the information may be *disclosed*. In addition, any instruction not to *disclose* information would be overridden by this provision. Accordingly, in this scenario, the counsellor would be permitted to *disclose* the information to the student's family and family physician, if he believes that the *disclosure* is necessary to reduce the risk of suicide.

Disclosures by facilities that provide health care

Unless the *individual* specifically requests otherwise, hospitals and other facilities that provide *health care* may provide the following information:

- confirmation that an *individual* is a patient or resident;
- the *individual's* general health status; and
- the location of the *individual* in the facility.

Disclosures about a deceased individual

Custodians may *disclose personal health information* about a deceased *individual* for the purposes of identifying the *individual* and informing *persons* that the *individual* is deceased and the circumstances of the death, where appropriate. In addition, information may be *disclosed* to close family members if the information is required to make *health care* related decisions.

Disclosures for health or other programs

The *Act* recognizes that *personal health information* is required for operating our publicly funded health care system. Custodians may *disclose personal health information*:

- for the purpose of determining or verifying eligibility to receive *health care* or related goods, services or benefits;
- to a *person* conducting an audit, reviewing an application for accreditation or reviewing an accreditation; or
- to a *person* who maintains a registry of *personal health information* for the purpose of improving the provision of *health care* or that relates to the storage or donation of body parts or bodily substances (i.e., Cardiac Care Network of Ontario (the registry of cardiac services); INSCYTE (CytoBase), London Health Sciences Centre (Ontario Joint Replacement Registry); and Canadian Stroke Network (Canadian Stroke Registry)).

Custodians may also *disclose personal health information* to a medical officer of health or similar public health authority.

Disclosures related to risks

Custodians may *disclose personal health information* if there are **reasonable grounds** to believe that the *disclosure* is necessary to eliminate or reduce a **significant risk** of serious bodily harm to a *person* or a group of *persons*. Custodians will have to exercise good judgment in determining what is a significant risk.

Disclosure related to care or custody

Custodians may *disclose personal health information* to the head of a penal or other custodial institution or *person* in charge of a psychiatric facility in which the *individual* is being held for the purpose of arranging for the provision of *health care* or making other decisions about the *individual*.

Disclosures for proceedings

There are certain legal *proceedings* that may require the *disclosure* of *personal health information*. The *Act* permits *disclosure* for a *proceeding* in which the custodian or an *agent* of the custodian is a party or witness. The custodian is also permitted to *disclose* for a *proceeding* to appoint a litigation guardian or legal representative for the *individual*. *Disclosure* to a litigation guardian or legal representative for a *proceeding* conducted on behalf of the individual is also permitted. Custodians may also disclose to comply with a summons, order or similar requirement issued in a *proceeding* or a procedural rule relating to the production of information in a *proceeding*.

Disclosure to successor

Custodians may *disclose personal health information* so that a potential successor may assess and evaulate the custodian's operation. Custodians may transfer *records* to a successor, as long as the custodian makes **reasonable** efforts to notify the *individual* before the transfer. If notification before the transfer is not reasonably possible, it should be done as soon as possible after the transfer.

Custodians may also transfer records for archival purposes. Records may be transferred to the Archives of Ontario or to another *person* who meets the requirements set out in the regulations. For example, the *person* must have in place reasonable measures to ensure that *personal health information* is protected against theft, loss and unauthorized *use* or *disclosure*, and measures to allow individuals to have access to their own *personal health information*. In addition, a *person* who intends to receive information for archival purposes must register with the *Commissioner*.

Example 9: For what purposes is a custodian permitted to *disclose personal health information*?

A dentist is moving to a location outside of Ontario and has put his private practice up for sale. Another dentist has indicated that she is interested in taking over the practice, but she would first like to review all of the dental *records* of each patient to assess and evaluate the business. The current custodian of the information and his potential successor have agreed that the dental *records* will be transferred to the potential successor dentist and, provided that the assessment shows the business to be profitable, the transfer of *records* to the successor will be considered to be permanent. Would this transfer of *personal health information* to a successor be permitted under the *Act*?

Can a custodian transfer *personal health information* to a potential successor for the purpose of allowing the potential successor to assess and evaluate the operations of the custodian?

The custodian is not permitted to **transfer custody and control** of *records* of *personal health information* to a potential successor for an assessment of the custodian's operations, by the potential successor. However, a custodian may *disclose personal health information* to a potential successor for this purpose. When such a ***disclosure*** is made, the potential successor must enter into an agreement with the custodian to keep the information confidential and secure and not to retain any information longer than is necessary for the purpose for which it is being disclosed.

Can a custodian permanently transfer *personal health information* to a successor?

A custodian may transfer custody and control of *personal health information* to his successor if the custodian makes reasonable efforts to give **notice** to *individuals* before the transfer is made. If it is not reasonably possible to give notice to *individuals* before transferring the *records*, notice should be provided as soon as possible afterwards.

Disclosures related to this and other Acts

In general, custodians are permitted to *disclose personal health information*, if the *disclosure* is permitted or required by other legislation. The *Act* lists certain pieces of legislation that permit or require the *disclosure* of *personal health information*, but **it is important to note that permitted *disclosures* are not limited by this list.**

Disclosure for research

The *Act* permits custodians to *use* and *disclose personal health information* for *research* purposes as long as certain requirements are met. The *researcher* must submit to the custodian an application, a research plan, and a copy of the approval of the *research* plan by a *research ethics board*. The *Act* describes what must be included in the *research* plan and matters that the *research ethics board* must consider in approving the *research* plan. The custodian must enter into an agreement with the *researcher* before *disclosing personal health information*.

The regulations set out specific requirements for *research ethics boards* and *research* plans. For example, a *research ethics board* must have at least five members, including one member with no affiliation to the *person* who established the *research ethics board* and one member with knowledge of privacy issues. *Research* plans must include, for example, a description of why consent to the *disclosure* of *personal health information* is not being sought from *individuals* and a description of all *persons* who will have access to the information.

Disclosure for planning and management of health system

Custodians are permitted to *disclose personal health information* for purposes related to planning and management of the health system. Such *disclosures* can only be made to entities that are specified in the regulations (i.e., Cancer Care Ontario, Canadian Institute for Health Information, Institute for Clinical Evaluative Sciences, and Pediatric Oncology Group of Ontario). Before such a *disclosure* can be made, the recipient of the information must have in place practices and procedures to protect privacy and to maintain confidentiality that have been approved by the *Commissioner*. The *Commissioner* must approve these practices and procedures every three years. With some exceptions, recipients of the information may only *use* or *disclose* the information for the purpose for which it was received.

Disclosure for monitoring health care payments

Upon the request of the Minister of Health and Long-Term Care, custodians **must** *disclose personal health information* for the purpose of monitoring or verifying claims for payment for *health care* or goods used for *health care* that is publicly funded.

Disclosure for analysis of health system

It is generally understood that the government needs information to plan and manage our publicly funded health care system. However, many people would be concerned if the government had unchecked access to their *personal health information*. In order to provide the government with the information it needs for this purpose, but at the same time respect the privacy rights of individuals, the *Act* sets up a novel and somewhat complicated set of procedures involving an intermediary body referred to as a **health data institute**.

Upon the request of the Minister of Health and Long-Term Care, custodians must *disclose personal health information* to a health data institute approved by the minister for analysis of the health system. Before making such a request, the minister must submit a proposal to the *Commissioner* for review and comment. The *Commissioner* must approve, every three years, the health data institute's practices and procedures to protect privacy and maintain confidentiality. The health data institute is required to perform the analysis requested by the minister and provide the results using only *de-identified* information.

Disclosure with Commissioner's approval

The health data institute may *disclose personal health information* to the Minister of Health and Long-Term Care or another *person* only if the minister believes the *disclosure* is in the public interest and the *Commissioner* approves the disclosure.

Restrictions on recipients

With some exceptions, a person who receives *personal health information* from a custodian must not *use* or *disclose* the information for any purpose other than the purpose for which it was *disclosed*. With some exceptions, the recipient must not *use* or *disclose* more information than is **reasonably** necessary to meet the purpose. These limitations do not apply if the recipient is a provincial or municipal government institution that is not a custodian.

As one would expect, none of the restrictions on recipients apply to the *individual* or the *individual's substitute decision-maker*. In addition, the recipient rules do not prevent a *person* from *using* or *disclosing* information received from a custodian for a purpose for which the *individual* has provided consent.

In addition, recipients who provide coverage for payment of medications or related goods and services may *disclose personal health information* to a pharmacist to assist the pharmacist in advising the *individual* or providing *health care* to the *individual*.

Example 10: For what purposes can a recipient *use* and *disclose* *personal health information* that he or she receives from a custodian?

The head of a prison has received *personal health information* about an inmate from a psychiatrist who undertook a psychiatric assessment of an inmate prior to the inmate being convicted of a series of murders. The psychiatrist disclosed the *personal health information* to assist the penal institution in making decisions about the placement of the *individual* within the facility. An academic *researcher* has asked the head of the prison for the *personal health information* of the inmate to be used for the purpose of a *research* project on the genetic predictors of serial murderers. The *researcher* is a well-known expert on serial killers and a *research ethics board* has approved the *research* project. Would the head of the prison be permitted to *disclose* the *personal health information* to the *researcher* for this purpose?

Can a person who receives *personal health information* from a custodian *use* or *disclose* the information for a purpose other than the purpose for which it was *disclosed*?

In general, a person who is not a *health information custodian* and to whom a custodian *discloses personal health information* can only *use* and *disclose* that information for the purpose for which it was *disclosed* or for the purpose of carrying out a statutory or legal duty. Since the head of a prison is not a *health information custodian*, as defined under the *Act*, the head is not permitted to *disclose* the information to the *researcher*. This is not the purpose for which the information was *disclosed* and the head does not have a legal or statutory duty to make such a *disclosure*.

Access to personal health information records

With some exceptions, the *Act* provides *individuals* with a right of access to *records* of their own *personal health information*. The right of access applies to a *record* that is dedicated primarily to the *individual*. If the *record* is not primarily about the *individual*, the right of access extends only to that portion of the *record* that is about the *individual*. However, a *person* does not have a right of access to personal health information in a *record* that is dedicated primarily to the *personal health information* of another *person*. The right of access does not apply to *records* that contain *quality of care information*, information required for quality assurance programs, raw data from psychological tests or assessments, and other specified types of information (i.e., information that is used solely for research purposes and laboratory test results).

Custodians must provide *individuals* with access to *records* containing their own *personal health information* unless:

- a legal privilege restricting *disclosure* applies;
- another law prohibits the *disclosure*;
- the information was collected or created for a *proceeding*;
- the information was collected or created during an inspection, investigation or similar procedure;
- access could result in serious harm to any *person* or the identification of a *person* who was required to provide information or who has provided the information in confidence; or
- the custodian is a government institution and the *disclosure* may be refused under certain provisions contained in access and privacy legislation that applies to government organizations.

If one of the above exceptions applies to the *record*, the custodian should sever the *record* and provide access to that part of the record to which the exception does not apply.

Requests for access should be in writing and must provide enough information to allow the custodian to identify and locate the *record*. Where the *individual* has not provided sufficient detail, the custodian is required to offer assistance. **It is important to note that nothing in the *Act* prevents a custodian from granting access to a *record* in response to an oral request or communicating with an *individual* about his or her *record* of *personal health information*.** Custodians are encouraged to provide access to records in the absence of formal written requests.

The custodian has 30 days to respond to a request for access. A 30-day time extension is allowed if meeting the 30-day time limit would unreasonably interfere with the operations of the custodian or if more than 30 days is required to undertake consultations necessary to respond to the request. Also, if the individual presents a convincing case for expedited access, the custodian is obliged to reduce the 30-day time frame, if it is possible to do so.

Before providing access, the custodian must take **reasonable** steps to determine the individual's identity. When granting access or providing a copy of a *record*, the custodian may charge a **reasonable** cost-recovery fee, unless specific fees are set by regulation. The custodian may waive the fee under appropriate circumstances.

An *individual* who is not satisfied with a decision of the custodian with regards to access to a record is entitled to complain to the *Commissioner*.

Example 11: Does the right of access extend to all types of *personal health information*?

An *individual* was subjected to a psychological assessment prior to receiving treatment in a rehabilitation clinic. During the course of treatment, the *individual* became involved in a dispute with his insurance company over payment for services. On the basis of *personal health information* obtained from the clinic, the insurance company had concluded that the *individual* had sufficiently recovered from his disability and terminated payment for further treatment. To assess the validity of the insurance company's claim, the *individual* requested access to all of his *records* of *personal health information* in the custody of the clinic. He was surprised when the clinic refused to provide access to the raw data from the original psychological assessment and instead provided only aggregate scores for each of the tests that were administered. Can the rehabilitation clinic deny an *individual* access to this information?

Can *individuals* be denied access to their own *personal health information*?

In general, *individuals* have a right of access to a *record* of *personal health information* in the custody and control of a *health information custodian*. However, this right of access does not extend to *records* that contain certain types of information such as *quality of care information* and raw data from standardized psychological tests or assessments. Accordingly, the clinic is not required under the *Act* to provide access to raw data from standard psychological assessments.

Correction

If an *individual* believes that a *record* of *personal health information* is not as accurate or complete as necessary for its purpose, the *individual* may make a written request to the custodian to correct the *record*. The custodian has 30 days to respond to the request. A 30-day extension is permitted if responding to the request within 30 days would unreasonably interfere with the activities of the custodian or more than 30 days is needed to undertake consultations to respond to the request.

The custodian is obligated to correct a *record* that is not accurate or complete, unless the custodian did not create the *record* or the *record* consists of a professional opinion made in good faith. Corrections can be made by recording the correct information in the *record*. This can be done by striking out incorrect information in a way that does not obliterate the information or by labelling the information as incorrect, severing it from the *record*, and storing in separately but linked to the *record*. If it is not possible to record the correct information in the *record*, the custodian must ensure that there is a system in place to inform anyone who accesses the *record* that the information is not correct and to direct the person to the correct information.

Once a correction has been made, the *individual* may require the custodian, **to the extent reasonably possible**, to inform anyone to whom the information has been *disclosed*. One exception is if the correction cannot **reasonably** be expected to affect the provision of *health care* or other benefits to the *individual*.

If the custodian refuses the correction request, the *individual* may prepare a statement of disagreement and require the custodian to attach it to the *record*. The *individual* may also require the custodian to make all **reasonable efforts** to *disclose* the statement of disagreement to anyone who would have been notified had a correction been made.

An *individual* who is not satisfied with a decision of the custodian with regard to the correction of a *record* is entitled to complain to the *Commissioner*.

Example 12: What *personal health information* is the custodian required to correct?

A woman sought treatment from a physician for a broad range of unusual symptoms. After a series of tests, the physician was unable to determine any physical cause for the symptoms and concluded that the cause was psychological. The woman decided to seek a second opinion, but was dissatisfied with the outcome when the second physician seemed to dismiss her symptoms without any medical tests. Finally, after seeking help from a series of physicians, the woman was diagnosed with a rare disease that was likely to be the cause of her symptoms. After recovering from her illness, the woman sought access to her *record* of *personal health information* from her current physician, who had diagnosed the rare disease. When access was granted, the woman was shocked to find that the physician whom she originally sought treatment from had made numerous remarks about her state of mental health and had diagnosed her as having a psychiatric disorder that caused her to seek treatment for made-up symptoms. The woman immediately made a request to her current physician to have the information in the *record* corrected. Although the current physician suspects that the information that was recorded was incorrect, he is not certain that the information was not correct at the time that it was recorded. Would the current custodian of the *record* be obliged to make the correction?

Is the custodian obliged to make the correction?

As a general rule, a custodian must grant a request for correction if the *individual* demonstrates to the satisfaction of the custodian that the information is incomplete or inaccurate for the purposes for which the information is used. However, a custodian is not required to correct a *record* that was not created by the custodian and with respect to which the custodian does not have sufficient knowledge, expertise and authority to make the correction. Also, a custodian is not required to correct a *record* that consists of a professional opinion or observation of a custodian, made in good faith. In this scenario, the custodian would not be required to make the correction since the part of the *record* in question was not created by the custodian and the custodian does not know if the information was correct at the time it was recorded. However, even if the custodian knew that the information was inaccurate and had the knowledge, expertise and authority to make the correction, he would not be obliged to make the correction since the information consists of a professional opinion that a custodian has made in good faith about the *individual*. Although the custodian is not required to make the requested correction, the patient is entitled to require him to attach a statement of disagreement as part of her *records*.

How will the *Act* be enforced?

Complaints

A *person* who believes another *person* has contravened or is about to contravene the *Act* may complain, in writing, to the *Commissioner*.

Upon receiving a complaint, the *Commissioner* may ask about other means the complainant is using or has used to try to resolve the matter; require the complainant to try to settle the matter with the *person* who is the subject of the complaint; or authorize a mediator to try to settle the matter.

Reviews by the Commissioner

If the issues in a complaint cannot be settled informally, the *Commissioner* may conduct a review of the complaint. It is the *Commissioner's* decision whether or not to conduct a review. In the absence of a complaint, the *Commissioner* also has the power to conduct a self-initiated review.

In conducting a review, the *Commissioner* may:

- enter any premises associated with the review;
- demand to review or copy any records, documents, and other material relevant to the review;
- summons the appearance of *persons* before the *Commissioner* and require them to provide evidence under oath;
- inquire into *records* of *personal health information*, under specified circumstances; and
- issue binding orders.

Are complainants compensated for damages?

A *person* affected by an order of the *Commissioner* or by conduct giving rise to a conviction for an offence can sue for damages for actual harm caused by the contravention or offence. Wilful or reckless conduct may include an award of up to $10,000 for mental anguish.

Are whistleblowers protected from retaliation?

Under the *Act*, no *person* can be fired, suspended, demoted, or disadvantaged in any way for:

- reporting a contravention or future contravention to the *Commissioner*;
- preventing any person from contravening the *Act*, or
- refusing to contravene the *Act*.

The *Act* also prohibits retaliating against a *person* because of a belief that the *person* may take any of these actions in the future. Under the *Act*, it is an offence to break the rules protecting whistleblowers.

Are custodians immune from liability?

Provided that custodians and other *persons* act **in good faith** and do what is **reasonable** under the circumstances, they are not liable for damages that result in relation to the exercising of their powers or duties under the *Act*.

Can custodians be convicted of offences under the *Act*?

It is an offence under the *Act* to:

- **wilfully** *collect*, *use* or *disclose personal health information* in contravention of the *Act*;
- make a request to access or correct a *record* of *personal health information*, **under false pretences,**
- **knowingly** make certain false statements in connection with a *collection*, *use* or *disclosure* of personal health information or access to a record;
- dispose of a *record* with the **intent to evade** an access request;
- **wilfully** dispose of a *record* in a manner that is not secure;
- *collect*, *use* or *disclose* the health card number in a manner that is inconsistent with the rules that apply to *persons* who are not custodians;
- **wilfully** obstruct the *Commissioner*;
- **wilfully** make a false statement to the *Commissioner*;
- **wilfully** fail to comply with an order of the *Commissioner*; or
- **retaliate** against a whistleblower.

Individuals (natural persons, not a company or institution) may be fined up to $50,000 and organizations may be fined up to $250,000 if they are found guilty of an offence.

Definitions

agent, in relation to a health information custodian, means a person who, with the authorization of the custodian, acts for or on behalf of the custodian in respect of personal health information for the purposes of the custodian, and not the agent's own purposes, whether or not the agent is employed by the custodian and whether or not the agent is being remunerated.

attorney for personal care means an attorney under a power of attorney for personal care made in accordance with the *Substitute Decisions Act, 1992.*

attorney for property means an attorney under a continuing power of attorney for property made in accordance with the *Substitute Decisions Act, 1992.*

capable means mentally capable, and "capacity" has a corresponding meaning.

collect, in relation to personal health information, means to gather, acquire, receive or obtain the information by any means from any source, and "collection" has a corresponding meaning.

Commissioner means the Information and Privacy Commissioner appointed under the *Freedom of Information and Protection of Privacy Act.*

de-identify means to remove any information that identifies the individual or for which it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify the individual.

disclose in relation to personal health information in the custody or under the control of a health information custodian or a person, means to make the information available or to release it to another health information custodian or to another person, but does not include using the information. "Disclosure" has a corresponding meaning.

guardian of property means a guardian of property or a statutory guardian of property under the *Substitute Decisions Act, 1992.*

guardian of the person means a guardian of the person appointed under the *Substitute Decisions Act, 1992.*

health card means a card provided to an insured person within the meaning of the *Health Insurance Act* by the general manager of the Ontario Health Insurance Plan.

health care means any observation, examination, assessment, care, service or procedure that is done for a health-related purpose and that:

- is carried out or provided to diagnose, treat or maintain an individual's physical or mental condition;
- is carried out or provided to prevent disease or injury or to promote health; or
- is carried out or provided as part of palliative care, and includes:
- the compounding, dispensing or selling of a drug, a device, equipment or any other item to an individual, or for the use of an individual, pursuant to a prescription; and
- a community service that is described in subsection 2 (3) of the *Long-Term Care Act, 1994* and provided by a service provider within the meaning of that Act.

health care practitioner means:

- a person who is a member within the meaning of the *Regulated Health Professions Act, 1991* and who provides health care;
- a person who is registered as a drugless practitioner under the *Drugless Practitioners Act* and who provides health care;
- a person who is a member of the Ontario College of Social Workers and Social Service Workers and who provides health care; or
- any other person whose primary function is to provide health care for payment.

health information custodian means a person or organization described in one of the following paragraphs who has custody or control of personal health information as a result of or in connection with performing the person's or organization's powers or duties or the work described in the paragraph, if any:

- a health care practitioner or a person who operates a group practice of health care practitioners;
- a service provider within the meaning of the *Long-Term Care Act, 1994* who provides a community service to which that Act applies;
- a community care access corporation within the meaning of the *Community Care Access Corporations Act, 2001*;
- a person who operates one of the following facilities, programs or services:
    - a hospital within the meaning of the *Public Hospitals Act*, a private hospital within the meaning of the *Private Hospitals Act*, a psychiatric facility within the meaning of the *Mental Health Act*, an institution within the meaning of the *Mental Hospitals Act*

or an independent health facility within the meaning of the *Independent Health Facilities Act*;

- an approved charitable home for the aged within the meaning of the *Charitable Institutions Act*, a placement co-ordinator described in subsection 9.6 (2) of that Act, a home or joint home within the meaning of the *Homes for the Aged and Rest Homes Act*, a placement co-ordinator described in subsection 18 (2) of that Act, a nursing home within the meaning of the *Nursing Homes Act*, a placement co-ordinator described in subsection 20.1 (2) of that Act or a care home within the meaning of the *Tenant Protection Act, 1997*;
- a pharmacy within the meaning of Part VI of the *Drug and Pharmacies Regulation Act*;
- a laboratory or a specimen collection centre as defined in section 5 of the *Laboratory and Specimen Collection Centre Licensing Act*;
- an ambulance service within the meaning of the *Ambulance Act*;
- a home for special care within the meaning of the *Homes for Special Care Act*;
- a centre, program or service for community health or mental health whose primary purpose is the provision of health care.

- an evaluator within the meaning of the *Health Care Consent Act, 1996* or an assessor within the meaning of the *Substitute Decisions Act, 1992*;
- a medical officer of health or a board of health within the meaning of the *Health Protection and Promotion Act*;
- the Minister, together with the Ministry of Health and Long-Term Care if the context so requires;
- any other person prescribed as a health information custodian if the person has custody or control of personal health information as a result of or in connection with performing prescribed powers, duties or work or any prescribed class of such persons.

health number means the number, the version code or both of them assigned to an insured person within the meaning of the *Health Insurance Act* by the General Manager within the meaning of that Act.

identifying information means information that identifies an individual or for which it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify an individual.

incapable means mentally incapable, and "incapacity" has a corresponding meaning.

individual, in relation to personal health information, means the individual, whether living or deceased, with respect to whom the information was or is being collected or created.

information practices, in relation to a health information custodian, means the policy of the custodian for actions in relation to personal health information, including:

- when, how and the purposes for which the custodian routinely collects, uses, modifies, discloses, retains or disposes of personal health information, and
- the administrative, technical and physical safeguards and practices that the custodian maintains with respect to the information.

parent does not include a parent who has only a right of access to a child.

partner means either of two persons who have lived together for at least one year and have a close personal relationship that is of primary importance in both persons' lives.

personal health information means identifying information about an individual in oral or recorded form, if the information:

- relates to the physical or mental health of the individual, including information that consists of the medical history of the individual's family;
- relates to the providing of health care to the individual, including the identification of a person as a provider of health care to the individual;
- is a plan of service within the meaning of the *Long-Term Care Act, 1994* for the individual;
- relates to payments or eligibility for health care in respect of the individual;
- relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance;
- is the individual's health number; or
- identifies an individual's substitute decision-maker.

person includes a partnership, association or other entity.

prescribed means prescribed by the regulations made under this *Act*.

proceeding includes a proceeding held in, before or under the rules of a court, a tribunal, a commission, a justice of the peace, a coroner, a committee of a College within the meaning of the *Regulated Health Professions Act, 1991*, a committee of the Board of Regents continued

under the *Drugless Practitioners Act*, a committee of the Ontario College of Social Workers and Social Service Workers under the *Social Work and Social Service Work Act, 1998*, an arbitrator or a mediator.

provincially funded health resource means a service, thing, subsidy or other benefit funded, in whole or in part, directly or indirectly by the Government of Ontario, if it is health related or prescribed.

quality of care information means information that:

- is collected by or prepared for a quality of care committee for the sole or primary purpose of assisting the committee in carrying out its functions; or
- relates solely or primarily to any activity that a quality of care committee carries on as part of its functions.

But does not include:

- information contained in a record that is maintained for the purpose of providing health care to an individual;
- information contained in a record that is required by law to be created or to be maintained;
- facts contained in a record of an incident involving the provision of health care to an individual, except if the facts involving the incident are also fully recorded in a record maintained for the purpose of providing health care to the individual; or
- information that a regulation specifies is not quality of care information and that a quality of care committee receives after the day on which that regulation is made.

record means a record of information in any form or in any medium, whether in written, printed, photographic or electronic form or otherwise, but does not include a computer program or other mechanism that can produce a record.

relative means either of two persons who are related to each other by blood, marriage or adoption.

research means a systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research.

research ethics board means a board of persons that is established for the purpose of approving research plans and that meets the prescribed requirements.

researcher means a person who conducts research.

spouse means either of two persons who:

- are married to each other, or
- live together in a conjugal relationship outside marriage and,
  - have cohabited for at least one year,
  - are together the parents of a child, or
  - have together entered into a cohabitation agreement under section 53 of the *Family Law Act*,

unless they are living separate and apart as a result of a breakdown of their relationship.

substitute decision-maker, in relation to an individual, means, unless the context requires otherwise, a person who is authorized under this *Act* to consent on behalf of the individual to the collection, use or disclosure of personal health information about the individual.

use, in relation to personal health information in the custody or under the control of a health information custodian or a person, means to handle or deal with the information, subject to subsection 6 (1), but does not include to disclose the information, and "use," as a noun, has a corresponding meaning.